Healthpoint

Information from the Division of Health Care Finance and Policy

ORGAN DONATION AND ALLOCATION

The altruistic act of organ donation has contributed to improved health and years of life for tens of thousands of transplant recipients since the first kidney was successfully transplanted at Peter Bent Brigham Hospital in 1954. Transplantation has become an increasingly frequent procedure with 492 major organ transplants performed at ten Massachusetts hospitals in 1998,[1] accounting for about $59 million in total hospital charges.[2] However, from 1988 to 1998 the number of patients on organ transplant waiting lists nationally increased by 302% (see figure on page 2). At the same time, donated organs increased by only 71% while the number of people who died each year waiting for organs increased by 225%.[3]

The growing disparity between organ supply and demand has intensified the debate over both the optimal means of promoting organ donation and the allocation system. A number of interested parties have a considerable stake in the ongoing debate. Among them are patients waiting for organs, hospitals and physicians defending existing programs or attempting to begin new ones, the United Network of Organ Sharing (UNOS) and the US Department of Health and Human Services each seeking greater administrative control, and states seeking to protect their citizens' and hospitals' interests. This issue of *Healthpoint* examines a number of current issues in organ donation and allocation, both nationally and in Massachusetts, and discusses a number of policy proposals designed to increase donation.

Division of Health Care
Finance and Policy

Two Boylston Street
Boston, MA 02116
(617) 988-3100

Louis I. Freedman
Acting Commissioner

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Background

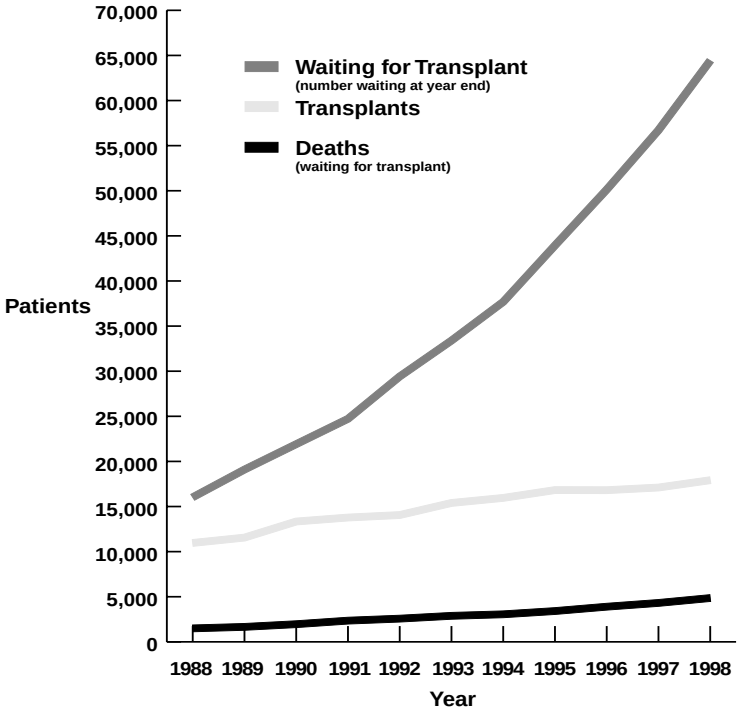
The National Organ Transplant Act (NOTA) was passed by Congress in 1984 to address the need for a more equitable and efficient system for the procurement and distribution of organs. The Act called for the formation of the Organ Procurement and Transplantation Network (OPTN), a collaborative effort of organ transplant hospitals and local organ procurement organizations (OPOs), to match donors to appropriate recipients. Since 1986, administration of the OPTN has been contracted to UNOS, a private non-profit organization. The nation is divided into 11 OPTN-established geographic regions within which there are 60 OPOs that administer the program to populations ranging in size from less than one million to 12 million. Every transplant hospital is affiliated with an OPO and maintains its own transplant patient waiting list. The New England Organ Bank (NEOB) is the OPO administrator for most New England hospitals.

Currently, when an organ becomes available, the local OPO searches for an appropriate recipient within its area based on clinical criteria such as size match and blood type. Clinical matching is attempted among the sickest (Level 1) patients first, then less sick patients in that OPO area, rather than Level 1 patients in another area. If no suitable match is found within the area, recipient matching is attempted within the OPTN region, then nationally. Challenging the federal allocation rules, six states (Arizona, Louisiana, Wisconsin, South Carolina, Oklahoma, and Texas) have passed legislation requiring organs donated in their state be offered first to patients listed with transplant centers in their state.

Recent federal legislation amends the current rules governing organ allocation, including the establishment of Organ Allocation Areas to cover at least nine million residents and greater standardization of hospital eligibility protocols. The intent is to create more equitable waiting times among patients. For example, from January 1994 to December 1996 the median waiting time for a blood type O liver patient in the New England region was 958 days, versus 123 days for the same type of patient in the southern states region.[4] In addition, OPTN regions that have a longer median waiting time for liver transplants tend to have a lower percentage of patients who receive a liver and a higher percentage who die while waiting for a liver.[4,5] By increasing the size of allocation areas, an available organ will be checked for compatibility with a larger pool of potential recipients and, consequently, a larger pool of the sickest patients, thereby making organs more available to those most urgently in need, and presumably reducing regional variation.

Opponents, most notably UNOS, counter that because the new rules will make organs available more frequently to the sickest patients (who tend to have worse outcomes), optimal utilization of organs will not be realized. Small and medium-sized centers tend to be in small OPO areas which facilitates access to organs for patients (from the most to the least sick) on their lists. These centers contend that the new rules will mean fewer organs for their patients, potentially decreasing their volume below the 12 liver transplant annual minimum needed to comply with the requirement for participation in Medicare.

Major Organ Transplants: US Trend



Source: United Network of Organ Sharing Scientific Registry data.

Massachusetts

Whereas a kidney donation is made from either a living (typically a family member) or cadaveric donor, liver, pancreas, heart and lung donors are primarily cadaveric, who most often die from intracerebral hemorrhage or accidental death (typically a motor vehicle accident). A look at the number of cadaveric donors in Massachusetts over time is a useful assessment of the relative success of donation initiatives in the state.

There are approximately 2,000 "candidate" deaths in Massachusetts per year,[6] defined as people under the age of 65 who die from intracerebral hemorrhage or accidental head injury (primarily sustained in motor vehicle accidents). From 1988 to 1997, the number of cadaveric donors at Massachusetts hospitals increased by 29%, from 83 in 1988 to 107 in 1997, relatively low compared to the 42% national increase in cadaveric donors during that period.[3] A useful indicator for the state trend in donation rates over time is the number of cadaveric donors per 1000 "candidate" deaths. By this definition, donation rates increased from 42.7 donors/1000 deaths (1991-1992), to 49.3 donors/1000 deaths (1996-1997). Although not all organs donated in Massachusetts are transplanted in Massachusetts hospitals, increased local donation undoubtedly would lead to the greater availability of organs for Massachusetts residents and its transplant hospitals.

Legislation

In 1983, Massachusetts established the Organ Transplant Fund (OTF) to assist residents with uncovered costs associated with organ transplant, typically immunosuppressive drugs. Transplant surgery itself is generally covered by insurance or, for the uninsured, the Uncompensated Care Pool. The OTF is administered by the Department of Public Health (DPH) and funded by private donations, most often via a voluntary indicator on the state income tax form. The OTF, the only voluntary state assistance program in the nation, has assisted 600 Massachusetts residents with over $2,000,000 in transplant related expenses in the last 13 years.

In 1998, HCFA amended the Medicare conditions of participation to require "routine referral" of all in-hospital deaths to the local OPO in a "timely" manner. Consequently, the specially trained NEOB staff, in collaboration with on-site medical staff, is able to make an assessment of organ donation potential and request consent from the family for donation. This situation typically results in higher rates of familial consent than if these tasks are left solely to the hospital staff.

Public Outreach

The primary, but vastly under-realized, channel for publicizing organ donation and signing up intended donors is the Massachusetts Registry of Motor Vehicles (RMV), whose license application and renewal forms ask applicants to indicate interest in the organ donor (OD) designation. However, RMV does not systematically provide information about organ donation by mail, on its website, or in its offices, nor does it routinely track the number of OD designated drivers. In contrast, Pennsylvania mandated comprehensive outreach in 1994, including the mailing of a "Greatest Gift" brochure with all registration renewal notifications, as well as deeming the OD designation on a driver's license sufficient to indicate legal consent. In Massachusetts, the OD designation is not considered legally binding; next-of-kin consent must be given for donation to occur. Although the quantitative effects of the Pennsylvania measures are difficult to determine ("routine referral" of all in-hospital deaths was mandated at the same time), the OPOs serving Pennsylvania report a 43% increase in organ donation from 1995 to 1998.[7]

Policy Implications

Ironically, improvements in transplantation medicine expanding the criteria for patient eligibility have led to an increase in the annual number of organ wait list deaths because the supply of organs cannot meet the demand. Alternative sources of organs, such as xenotransplantation (animal organs altered with human genes) or the genetically engineered "growing" of organs, are years

from practical use and carry with them uncertain public health risks. However, a number of state initiatives could increase the potential for donation in Massachusetts.

DPH is already undertaking an initiative with NEOB and trauma-center hospitals to standardize donation protocols by adopting those of the hospitals with the highest donor rates. In addition, the Massachusetts Health Care Proxy, which all hospitals are required to offer inpatients, could be used as a vehicle to increase the donation rate. Currently, the form asks patients to designate an agent who would have the authority to make all health care decisions for them in the event they become unable to do so. Specifically requesting consent for organ donation on the proxy would legally confirm the patient's wishes in the event of death.

A number of changes could potentially improve upon the use of the RMV as a resource. First, organ donation information should be made available proactively to anyone conducting business with the RMV. Second, aggregate data on license-designated organ donors should be collected via the registry database. This data would be useful in assessing future donation initiatives and policy. Third, the legislature should seriously consider making the OD designation legally binding.

In the coming months, a number of legislative and judicial developments bear watching, including court rulings on the allocation rule challenges by several states, and the possibility of a moratorium on the amended allocation rules. However, as the interested parties compete for their interests, the critical difference for patients continues to be the lack of available organs. Until alternative organ sources become safe and practical, we must improve upon our efforts and continue to work towards the development of effective organ donation policies nationally and locally.

Endnotes

1. Major organs include: kidney, liver, pancreas, heart and lung.
2. Massachusetts hospital inpatient case mix data.
3. United Network of Organ Sharing Scientific Registry data as of 9/14/99.
4. From "Fostering Equity in Patient Access to Transplantation: Differences in Waiting Times for Livers," US Department of Health and Human Services Office of the Inspector General, May 1999, OEI-01-99-00210.
5. Death rates are not case mix adjusted.
6. Massachusetts Community Health Information Profile data.
7. Pennsylvania Department of Health press release, 6/9/99.

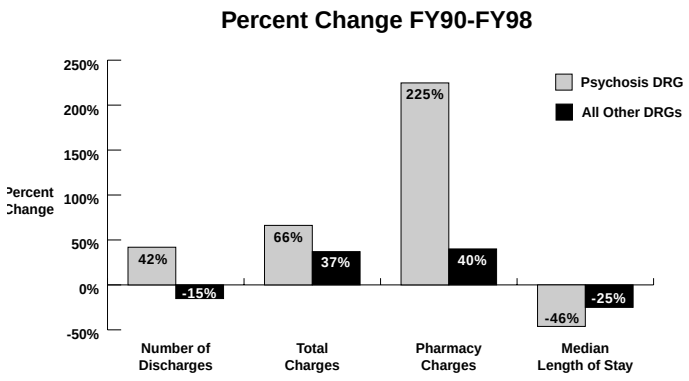
More Information

If you would like to learn more about becoming an organ donor, please contact the New England Organ Bank at 1-800-446-6362.

Did you know?

Psychosis Counters Trend in Declining Admissions

Patient discharges for psychosis (DRG 430) increased 42% while discharges for all other DRGs decreased 15% between FY90 and FY98. In FY98, psychosis accounted for more non-birth-related discharges (26,264) than any other single DRG and accrued the highest percentage of all charges. Its share of charges, especially its associated pharmacy charges, has risen markedly from the beginning of the decade. While the number of discharges with a psychosis DRG has increased, median length of stay has declined more than for all other DRGs.



Source: Massachusetts Division of Health Care Finance and Policy hospital discharge data.

Staff for this publication:

Bruce Anderson
Maria Schiff
Maxine Schuster
Heather Shannon